# Lyme Disease Advisory Committee Meeting March 20, 2006, Sacramento, California

The meeting of the Lyme Disease Advisory Committee (LDAC) was held on March 20, 2006, in Sacramento, California.

#### Committee members in attendance

Victoria Deloney, Ph.N., Sacramento County Public Health
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Peggy Leonard, Lyme Disease Resource Center
Susie Merrill, Lyme Disease Support Network
Scott Morrow, M.D., M.P.H., California Conference of Local Health Officers
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

## Committee members not in attendance

James Miller, Ph.D., University of California, Los Angeles

#### Other attendees

Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services Approximately 30 people representing the interested public and public agencies

# I. Opening Comments

Mr. Parlier brought the meeting to order at 9:50.

# II. Update on Laboratory Reporting of Lyme Disease

Dr. Ben Sun of the Surveillance and Statistics Section gave an update on laboratory reporting of Lyme disease (LD) beginning with an overview of public health reporting. Briefly, local health departments (LHD) are alerted about most reportable disease cases from the diagnosing physician. The LHD evaluates if the case fits the surveillance criteria as established by the Council of State and Territorial Epidemiologists (CSTE - <a href="http://www.cste.org/">http://www.cste.org/</a>). Cases that meet the definition are sent to the California Department of Health Services (CDHS). The case report is evaluated again at CDHS, included in the State database, and the report is finally passed on to the Centers for Disease Control and Prevention (CDC). Dr. Sun emphasized that for all reportable diseases, CDHS follows the case definitions as outlined by CSTE. With passage of Assembly Bill 1091 (2004, McLeod), LD became laboratory reportable, which means that laboratories must forward positive test results to the local health department in which the ordering physician practices. The local health department then contacts the ordering physician to gather appropriate information about the patient. This will likely increase the number of reported cases because the reports will serve as an additional source of information to the local health departments that a physician

(who may not have otherwise reported) suspects a case of LD. Each local health department has their own policy on what to do with laboratory reports that do not fit the surveillance criteria. They do not forward them on to CDHS.

Questions from the Committee to Dr. Sun pertained to laboratory compliance in reporting, number of commercial laboratories that test for LD, and notification of LHD about the changes made to the reportable disease list. Dr. Sun replied that laboratory reporting has good compliance because they have a history of routine reporting, probably less than a dozen commercial laboratories test for LD, and that LHDs were made aware of the change in regulations through communications from the California Council of Local Health Officers (CCLHO) and CDHS.

Dr. Morrow relayed information he had gathered regarding LD cases reported from San Mateo County to CDHS. He noted that of the 34 LD cases reported from San Mateo to CDHS between 2004 -2005, 27 were classified as not fitting the surveillance case definition, yet all of the cases were treated. He supplied additional demographic statistics on the patients. He felt that it is important to be able to keep track in some way of all the cases that are reported and treated, regardless if they fit the surveillance criteria.

Dr. Kramer noted that the appropriate way to address a change in a specific disease reporting protocol is to forward this to the CCLHO reporting subcommittee since that is the avenue stated by AB 1091 for making changes to the reportable disease list. She reminded the Committee that the point of a surveillance case definition is that it allows consistent monitoring of trends over time and across states.

Dr. Morrow and Ms. Leonard expressed that they felt the Committee should make suggestions on the LD case reporting form so that cases that fit the surveillance criteria and those that do not will all be tracked.

Dr. Sun reiterated that discussion of creating a subset definition of a specific disease should be with the LHDs who will be most involved in tracking disease occurrence.

There was Committee discussion on the utility of the LDAC making recommendations on LD reporting.

Dr. Stricker made a motion to form an ad-hoc committee to investigate LD reporting in California under AB 1091.

Ms. Leonard seconded the motion.

Discussion by the Committee concerned the current LD case report form and the process followed to fill it out. Dr. Sun clarified that the LD case report form is from

CDHS, and is made available to the LHDs. Either the LHDs fill the forms out when they contact the physician or they send it to the diagnosing physician who fills it out and then returns it to the LHD. Dr. Stricker stated that the CSTE case definition only catches acute cases and most cases are not acute.

The floor was opened for public comment.

One public member asked if a California resident is tested out of state, how is the case reported? Dr. Sun stated that the lab is required to report it to CDHS if a person who is a California resident tests positive to *Borrelia burgdorferi*.

A vote was taken on the motion. The motion passed with 6 ayes and 1 abstention (Dr. Kramer).

The Committee discussed who will serve on the reporting subcommittee. Drs. Stricker and Morrow and Ms. Leonard volunteered to serve. Dr. Kramer said someone from the Division of Communicable Disease Control would also be appointed to the subcommittee. The meeting time will be determined at the LDAC teleconference to approve the minutes.

Continued questions by the Committee on laboratory reporting included: the status of electronic reporting, who do LHDs contact if they have questions about reportable diseases, and who sets policy on what is told to LHDs. Dr. Sun replied that electronic reporting is in the testing phase, LHDs contact Dr. Sun if they have questions and he forwards these calls to those people with the expertise in that specific area. If a question is commonly repeated, then explanations are sent out to all LHD or discussed at CCLHO meetings. He noted that recently several diseases were added at once to the reportable disease list so that did create some confusion.

## III. CDHS progress report

Dr. Kjemtrup gave an update on CDHS activities regarding Lyme and other tickborne disease education and surveillance. Because this year represented the fifth year of accomplishments by the LDAC, Dr. Kjemtrup outlined a brief history of LDAC and listed the goals achieved since inception in 1999. She also reviewed the educational activities for 2005, gave a surveillance update for 2005, and listed some goals and emphasis for this year.

Briefly, the major accomplishments for the past five years included a LD brochure updated yearly, new tick warning signs, tick ID card, posters on tick borne disease awareness and prevention for work places and health fairs, articles for physicians, and expansion of website to include data on *Borrelia burgdorferi* in ticks in California. Increased outreach through doubling the number of press releases per year, sharing information with non-traditional partners, and on-going talks with local agencies and partners also continues.

In 2005, press releases generated several responses from radio and print media. Other less traditional publications such as the *California Agricultural Alert* and *Comstock Magazine*, a business journal, also printed stories about Lyme disease using information provided by CDHS. Wallet-sized tick ID cards were printed and massively distributed this year, and the brochure and a 1-page information sheet on tick-bite prevention was included in the state-wide immunization information mail-out to all schools. Presentations by Vector-Borne Disease Section biologists on ticks and tick-borne diseases were given throughout the state to various agencies and educational groups including National Forest Service, Caltrans, Vector control agencies, University of California, and the Center for Occupational Health.

This year, efforts will focus on developing a brochure and bookmark for children, and issuing a physician questionnaire to reassess knowledge and awareness of California physicians about tick-borne diseases. Radio PSAs from the Missouri Department of Health were presented because they had agreed to allow CDHS to change the tag line and use them as well.

Surveillance activities in 2005 included the testing of over 1,900 *Ixodes pacificus* ticks from throughout the state for *B. burgdorferi* by the United States Army Center for Health Promotion and Preventive Medicine-West (USCHPPM). A study to assess occupational exposure to ticks among U.S. Forest Service workers was begun by VBDS in 2005.

Committee questions focused on the distribution of *B. burgdorferi* in California, the budget for testing ticks, methods for collecting ticks, and how public messages are tied to surveillance information.

Dr. Kjemtrup replied that *I. pacificus* ticks have not been recovered from Alpine and Modoc Counties, despite efforts to find them. The budget for testing ticks covers testing for 2,000 *I. pacificus* ticks by the real-time polymerase chain reaction (PCR) method. A hypothesis-driven or risk-based approach is used to decide what areas should be tested, e.g. if an area is frequented by many visitors, knowing the prevalence of *B. burgdorferi* would help understand people's risk of Lyme disease in that area. Since Dr. Lane's publication that nymphal ticks are more frequently encountered on logs and tree trunks, surveillance techniques for nymphs by VBDS personnel have included flagging on logs and tree trunks. The press releases are issued to coincide with the general seasonality of *I. pacificus*: fall for increased adult activity and spring for increased nymphal tick activity. The focus of press releases is tick bite prevention.

Mr. Parlier told Dr. Kramer to please thank all VBDS staff for the work they do.

#### IV Committee updates

Dr. Robert Lane reported on work from his laboratory that has implicated tree squirrels as an important reservoir for *B. burgdorferi* in woodland habitats. In collaboration with VBDS, he was able to isolate *B. burgdorferi* from tree squirrels collected through West Nile virus surveillance. He also recounted his recent studies documenting that sitting on logs or against tree trunks was an important risk factor for acquiring nymphal *I. pacificus* ticks. He emphasized that a last line of defense after checking yourself for ticks is to check your bedding after being in an area where you might have acquired a tick.

A member of the public inquired about the utility of tick testing. Dr. Kjemtrup replied that CDHS has issued recommendations (available on the website - <a href="http://www.dhs.ca.gov/ps/dcdc/disb/lymedisease.htm">http://www.dhs.ca.gov/ps/dcdc/disb/lymedisease.htm</a>) that testing a tick that has bitten you is not useful for treatment decisions for a variety of reasons including the delay in getting test results and problems associated with the test itself. A negative test results may also provide an individual with a false sense of security as the individual may have been bitten by other potentially infected ticks that were not detected.

Dr. Stricker noted that he gave a talk on LD at a Nurse Practitioners' meeting where there was a lot of interest in LD and that he hopes the California Lyme Disease Association (CALDA) can work with CDHS to provide educational material.

# V. Revisit and update goal matrix

Dr. Kjemtrup reviewed the goal matrix updated from the last meeting and noted the items that have been completed and are in progress (Appendix A).

#### VI. Brochure for children

A draft brochure on tick-bite awareness and prevention for children developed by CDHS was presented to and discussed by the Committee. Specific suggestions by the Committee were:

- Use a cartoon, possibly an animal, which can carry the message throughout the brochure.
- Emphasize what is the actual size of a tick.
- Decrease the number of different fonts.
- Include "brushy" after "grassy"
- Add "and tuck shirt into pants" after "Tuck pants into socks or boots".
- Change the phrase, "Wear insect repellent like DEET" to "Wear insect repellent with DEET".
- Add that ticks should be removed "quickly and properly".
- There needs to be a statement about how to remove a tick from a dog.
- Add "or a tissue" to "Grab the tick close to your skin with tweezers.."
- Add a statement about apply an antibiotic ointment after removing a tick.

- Change "adult" to "grown up"
- In quiz, make reference to "Golden Gate Bridge" not "42 and Broadway".
- Several small grammatical changes were also noted.

Public comment included the following suggestions:

- Come up with slogan for tick safety that will appeal to kids.
- Add something to encourage carrying tweezers when hiking.
- Try to distribute to outdoor stores like REI that carry tick-removers.

#### VIII. Children's bookmark

A bookmark intended for children designed by CDHS was presented to and discussed by the Committee. In general, comments on brochure will apply to bookmark. Additional comments included:

- Use the same cartoon character as brochure.
- Use as few words as possible.
- Suggest another product such as a compact disk rather than a bookmark.

# IX. Physician Survey: Awareness of Lyme Disease in CA

Dr. Kjemtrup presented a draft of a survey intended for physicians to assess their awareness and knowledge of tick-borne diseases and prevention in California. This survey would be a follow-up to the survey conducted two years ago and the timing is appropriate in light of the change in LD reporting to laboratory reporting. The survey is designed to be administered through an on-line service that will facilitate data collection.

The Committee discussed that taking a more structured methodological approach, e.g. a phone survey of a selected population rather than soliciting self-selected responses, would provide more meaningful information for directing future education efforts towards physicians. Offering incentives such as tick cards would also be useful. Dr. Stricker suggested that the California Primary Care Association may be a good association to approach and offered to send the contact information.

Specific comments on the questionnaire included:

- Add question, "Are you aware of CDHS' educational program on Lyme disease?"
- Add question, "Where would you go for information about LD and treatment?"
- Include *Bartonella* in list on question of tick-borne diseases physicians think may occur in California.
- Ask about physician's belief in the presence of tick-borne diseases in the "region" in which they practice rather than "county".

 Include an introduction on the importance of the survey and thank-you at the end.

#### X. Public Comment

Two members of the public relayed their experience in getting diagnosed and treated for LD, including encountering physicians who suggested that LD does not exist in CA and refused to offer antibiotic treatments. Both members emphasized the need to reach out to physicians with information about LD.

One member of the public asked for clarification from Dr. Lane on the ability of mosquitoes to transmit LD. Dr. Lane emphasized that his work did not show that mosquitoes can transmit LD. He stated that mosquitoes may pick up the spirochete but no evidence exists that they can transmit it.

Another member of the public relayed her young daughter's experience in being diagnosed and treated for LD. She felt that if physicians were better educated about LD, her daughter's illness would have been diagnosed and treated earlier and her daughter would not have had to suffer so long. She emphasized that the State of California needs to take a stand on LD.

Another member of the public noted that working with CDHS is cumbersome but progress has been made. She stated that CALDA worked with CDHS to encourage the passage of AB 1091. She presented information that suggested that LD is under-reported in California and that there are potentially 133,550 cases of LD each year in CA with an estimated cost of 9 – 14 billion dollars.

A member of the public presented 3 emails of people who could not attend and who relayed their experience with LD.

Mr. Parlier thanked the audience for sharing their experience and offering insight on LD in CA and also thanked CDHS for the presentation.

The meeting was adjourned at 3:15 p.m.

Appendix A

# Goals recommended by the Lyme Disease Advisory Committee (Reviewed March 20, 2006\*)

Goal Area	6 months	12 months	18 months	2 years	3 years
Educate Medical Community	Assess physician awareness on LD in CA     Results published in Medical Alert     Include a blurb on Lyme disease in the weekly CD brief, an electronic newsletter that goes out to all local HD. (Sent via CCLHO mailing list)     Send brochures to all California hospitals for inclusion in their libraries.     Provide brochures and LD information to nurses, particularly school nurses, and nurse advice lines.	Develop document of different tests used for LD dx with references for health care providers Contact HMOs and inform them about current educational material. Send "alerts" to hospitals to correspond with DHS press releases on the disease. Public Health Grand Rounds	Get brief articles into HMO newsletters. Continue to make brochures available to local health departments. Include information on local incidence; and encourage the HD to send brochures to local physicians.	Conduct follow-up assessment on CA physician knowledge, awareness on Lyme disease in CA Flyers suitable for posting in physician offices developed and posted on website Tick testing Q and A developed and will be posted on website.  "Awareness of Tick-borne disease in CA" presentations for Grand Rounds as requested	
Educate General Public	<ul> <li>Target high risk groups for presentations</li> <li>Post areas of risk with information about prevention</li> <li>Put pictures of ticks on the website as a fact sheet or include a key.</li> </ul>	<ul> <li>Provide consultation to and collaborate with LD support groups to facilitate public education</li> <li>Make wallet-size cards with tick ID on one side and tick removal on the other. Include different tick species as well as engorged adult ticks. Include information that Ixodes pacificus bites more people than any other species of tick.</li> </ul>	Produce a public service announcement. Provide advice protocols to parks so they know what to say when people call for information on ticks. Develop PSA's (public service announcements) for radio Put data on website of ticks removed from people and tested for Borrelia burgdorferi.	Large tick bite prevention poster suitable for health fairs developed and posted on website     Updated tick-database and map on website	
Educate School Children	Catalogue educational material for children available at local mosquito and vector control districts.  Encourage local agencies to send brochures to school librarians within their jurisdiction.	Use the website to provide information for school-age children (tick i.d. and coloring pages, etc.)	Create a bulletin board kit that teachers, libraries or school nurses can use in the classroom.		
Risk Assessment	Create LDAC subcommittee to meet with Statistics and Surveillance section to investigate possibility of making LD laboratory reportable	<ul> <li>Investigate possibility of having "two- tiered" reporting system, e.g. maintaining records on cases that fit surveillance criteria and those that do not.</li> </ul>		Encourage and facilitate local vector control districts to conduct nymphal and adult tick surveillance; provide consultation as needed     Solicit grants for expanding ticktesting for surveillance .	<ul> <li>Encourage tick studies in every county showing nymphal infectivity rates.</li> </ul>
Disease Prevention		<ul> <li>Increase awareness such that legislative funding is made available for LD research</li> </ul>			

\*Key: *Goals in italics* = in progress

Goals in bold = accomplished

Additional accomplishments in blue Ariel font